Correcting Deficiencies in HIV/AIDS Care for Transgendered Individuals

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Studies suggest that transgendered individuals are at high risk for acquiring HIV through injection drug use and sexual risk behaviors. Beginning efforts are being directed to identify the unique needs and concerns of these individuals and to develop culturally sensitive programs that will be successful in recruiting and retaining these individuals in drug abuse and HIV treatment services. These efforts include examining the available and needed services from the perspectives of both the transgendered community and health care professionals. This article reviews the phenomenon of transgenderism and the social context that places these individuals at risk for HIV. Additionally, this article proposes some guidelines for those who are in positions responsible for designing, evaluating, and implementing existing health care services to transgendered populations.

Key words: *transgendered populations, care deficiencies, culturally sensitive treatment*

Increasing evidence demonstrates that the rate of HIV infection among transgendered individuals, particularly male-to-female, is high and that the risk of infection may even surpass that for bisexual and homosexual men (Nemoto, Luke, Mamo, Ching, & Patria, 1999; San Francisco Department of Public Health, 1999; Sykes, 1999). Many transgendered women (i.e., male-to-female [MtF]) are at risk because of risky sex or sharing needles in the injection of hormones or intravenous drugs (Nemoto et al., 1999; San Francisco Department of Public Health, 1999; Sykes, 1999). Although data are scant on transgendered men (i.e., female-to-male [FtM]), there is some evidence to suggest that this group is also at risk due to injecting hormones with shared needles and having unprotected anal sex (San Francisco Department of Public Health, 1999).

Correlates for risk behavior in transgendered individuals are many and include low self-esteem, substance abuse, and economic necessity, that force them to resort to survival sex (Bockting, Robinson, & Rosser, 1998; Clements, Wilkinson, Kitano, & Marx, 1999). Although there have been far fewer studies of this population, compared to that of gay and bisexual men and commercial sex workers, the HIV risk among this group causes alarm. Studies have shown that among sex workers, transgendered individuals had higher rates of HIV infection than their nontransgendered sex worker counterparts in the same neighborhoods (Boles & Elifson, 1994; Moden et al., 1992). One study reported that MtF individuals were more likely to take sexual risks, in terms of the number of sex partners in a given 30-day period and in the last 6 months, than either homosexual or bisexual males, anyone in commercial sex activities, or anyone having

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a steady partner who injected drugs (Nemoto et al., 1999). Other studies indicate that many MtF individuals are at risk due to engaging in unprotected anal intercourse in the context of commercial sex work injection drug use (Clements, Marx, Guzman, Ikeda, & Katz, 1998; Loney, 1998; Moden et al., 1992; Week, 1998).

These individuals may be difficult to target with traditional prevention campaigns, in addition to fearing discrimination, should they seek services such as HIV/AIDS education and testing (Bockting et al., 1998; Clements et al., 1999). The insensitivity of health care professionals has been cited as a reason that these and other services are not accessed. Indeed, reports of insulting/insensitive comments and behavior by health care providers suggest that services are severely lacking in the provision of culturally sensitive interventions and potentially within the provision of HIV disease–related health care (Bockting et al., 1998; Clements et al., 1999). The purpose of this article is to present information concerning transgendered men and women in addition to the problems experienced by them within health care settings. Guidelines will also be presented that, when implemented, would create more effective prevention and treatment services by creating a safe and secure environment for transgendered men and women. Such guidelines will increase the likelihood that services will be accessed and the client retained within treatment.

Transgendered Population

Transgender refers to the population of individuals who do not conform to traditional conceptions of sex and gender. It should be noted that this does not refer to how people self-identify but is merely a shorthand term used to refer collectively to cross-dressers, transsexuals, *travestis*, or *hidjras* (the last two are subcultures of transgender individuals; Kulick, 1998; Nanda, 1990). Terms related to or associated with transgendered individuals are presented and defined in Table 1. The reality is that there are a variety of self-identifications that should be used when referring to specific individuals or groups of people.

Sexual orientation is distinct from one's gender identity. Whereas sexual orientation refers to sexual attraction, transgender refers to one's gender identity and presentation depending on whether individuals

Table 1. Definitions of Transgender-Related Terms

Androgyny: a term used to indicate the strong presence of both masculine and feminine gender role characteristics in a given individual.

Drag queen or drag king: a term referring to a subpopulation of the transgendered population that appear as women or men, dressing for exhibitionist reasons or for entertainment.

Gender dysphoria: a term used to indicate a state of feeling or believing that one is not really a member of one's anatomical sex; sometimes referred to as feeling born the wrong sex.

Gender presentation: refers to the way members of each gender conduct themselves socially, including the clothing they choose, their mannerisms, and even their speech patterns.

Gender reassignment surgery: surgery for transsexuals, designed to re-form male genitals into female genitals or female genitals into male genitals. Also referred to as sex reassignment surgery. For MtF transsexuals, this can involve vaginoplasty, orchiectomy, and labiaplasty. For FtM transsexuals, it can involve bilateral mastectomy, phalloplasty, metaoidioplasty, hysterectomy, and vaginectomy.

Gender role: a set of culturally prescribed behaviors that determine how members of each gender are expected to behave in a particular society.

MtF and FtM: terms used to describe categories of transgendered, transsexual, or transvestite populations; MtF refers to biologic sexed males who view themselves as female, whereas FtM refers to biologic sexed females who view themselves as male.

Sexual orientation and identity: refers to one's sexual preferences and perceived sexual role one occupies in any interpersonal encounter.

Transgenderism: a term used to describe cross-gendered presentation. An umbrella term often used to refer to transsexuals, transvestites, intersexed, and other cross-gendered people into one category. Also a term used to describe an identity of a socially reassigned person who chooses not to have genital surgery.

Transsexualism: sometimes believed to be the same as transgenderism; this term is most associated with diagnostic nomenclature, for example, the *Diagnostic Statistical Manual* (*DSM-IV*) from the American Psychological Association (APA), which views the condition as a state of extreme gender dysphoria that has persisted without fluctuation for at least 1 to 2 years. Transsexuals sometimes elect to pursue reassignment therapy with the use of exogenous hormones or sex reassignment surgery.

Transvestism (cross-dressing): refers to wearing clothing normally associated with the opposite sex for emotional and/or sexual gratification. It can involve any amount of time commitment. It does not necessarily, but can, involve cross-gendered identity.

Two-spirit (berdache): a word used to refer to a social role among some Native American tribes in which people of one biological sex lived their lives as members of the other biological sex. Berdache is the European term given to this population.

Adapted from Rice (1999). Permission granted from Matt Rice.

perceive themselves as being man, woman, or a combination of the two. As such, it is not unheard of for transsexual men (FtM; female birth assigned but identifying and presenting as men) to also identify as gay men. The same reasoning can be used for transsexual women (MtF) who identify as lesbian.

The incidence of transsexualism, based on studies outside the United States and using different measures of prevalence, is approximately 1 per 20,000 to 50,000 persons, with more MtF than FtM trans- gendered individuals (Weitze & Osburg, 1996). Prevalence rates have been shown to vary across countries. Bakker, van Kesteren, Gooren, and Bezemer (1993) reported the prevalence of transsexualism among persons native to the Netherlands by counting the number of persons seen by psychiatrists and psychologists who were subsequently hormonally treated and underwent sex reassignment therapy. They found that the prevalence rate for transsexual individuals was 1:11,900 MtF individuals, compared to 1:30,400 FtM individuals, a ratio of 2.5 MtF to 1 FtM transgendered individuals. In Sweden, transsexuality has been reported to be found equally in MtF and FtM individuals (Landeb, Walinder, & Lustrom, 1996). However, the prevalence of transsexualism may be underestimated. Most studies tend to utilize people sampled from gender clinics and mental health settings, which may underrepresent the prevalence, as many individuals do not (or cannot) access such services. Within some literature, transgenderism is ambiguously conceptualized, lending to the confusion about prevalence. For example, transgendered/transsexual women are believed to be gay or bisexual men or as men who have sex with men. Transgenderism is often confused with sexual orientation, whereas what may be the case is that their sexual orientation is "heterosexual" rather than gay or bisexual. Transgendered individuals' sexual orientation can vary widely; thus, to correctly identify individuals' sexual orientation, one must be careful to ask the client without presuming their gender identity or sexual orientation.

Transgendered individuals can also vary by race/ethnicity, class, gender, sexual orientation, and a host of other characteristics, which make them unique and difficult to group. These individuals should not be considered as a homogeneous group of people, and their differences need to be taken into account by health care providers.

In the transgendered population, those assigned male at birth may identify as women (transgendered women) and those assigned female at birth may identify as men (transgendered men). Some individuals may be very political when it comes to gender identification and presentation, whereas others are more conservative. Different cultures also have different ways of ascribing roles and labels and vary in the ways they explain and incorporate gender variance. Frequently, personal access to resources (e.g., information, education, monetary resources, social networks, and emotional strength) can play a role in whether and to what degree one identifies and presents publicly as transgender.

Regardless of the reason, there is a wide range of potential presentations or ways individuals conduct their daily lives. Typically, society tends to group individuals together into one or more classifications (e.g., transvestite or transsexual) without fully accounting for or appreciating the full range of possible identifications and how self-definitions influence individuals' lifestyles and preferences. The use of the terms *transgender*, *transsexual*, and *transvestite* is problematic in that these terms are not adequately defined so that society tends to label these individuals as either transvestite or transsexual without trying to understand their unique life experience. For example, Boles and Elifson (1994) examined "transvestite" sex workers and basically delineated them by their level of commitment to "transvestism." Strongly committed transvestites identify and present a consistent social identity as women, whereas marginally committed transvestites maintain a social and psychological identity of a man. From this perspective, transsexual becomes a subcategory of transvestite rather than a separate category altogether as presented in other studies (Bolin, 1997).

The Social Context of Transgenderism and Subsequent Challenges for Health Services

Transgendered individuals are a diverse group with some issues that are common to all, namely, a lack of societal understanding and acceptance. Health care

providers should be better positioned to understand the social dilemmas and frequent discriminatory treatment faced by these individuals. Yet, in many instances this is not the case. Providers need to gain a more thorough understanding of the transgendered client to provide culturally sensitive prevention and treatment programs.

Discrimination and Violence

Transgendered individuals are likely to experience some form of discrimination and/or violence. Lombardi, Wilchins, Priesing, and Malouf (in press) reported that approximately 60% of the subjects in their study experienced some form of harassment and/or violence sometime within their lives, and 37% experienced some form of economic discrimination. Violence and discrimination have been found to have negative effects in other populations. Garnets, Herek, and Levy (1992) stated that experiences of violence and harassment can significantly affect the mental health of gay men and lesbians, which, in turn, could result in maladaptive coping, including high rates of substance abuse, which may further increase risk for HIV infection.

Transgendered Youth and Commercial Sex Workers

All individuals practicing unsafe behaviors are at risk of HIV infection. However, two subgroups within the transgendered community are in greater need of health services and HIV prevention support. These are transgendered youth and commercial sex workers.

Researchers report that social and psychological problems often experienced by transgendered youth put them at exceptionally high risk for substance abuse. Savon-Williams (1994) reports that verbal and physical abuse may influence substance use, prostitution, and suicide in gay, lesbian, and bisexual youth. As such, transgendered youth are at a very high risk of HIV infection (Kreiss & Patterson, 1997; Rodgers, 1995). Savon-Williams (1994) also identifies that "cross-gendered" youth are most likely to be abused because they do not meet the cultural ideals of gender-appropriate behaviors and roles.

Health care services have previously focused narrowly on the problems of transgendered populations (e.g., hormones and surgery), ignoring other issues critical to the care of these individuals, and particularly the care of transgendered youth. Transgendered youth often have limited resources available (Kreiss & Patterson, 1997). Many times transgendered teens run away or are evicted from their homes and families. This results in many of them facing problems experienced by homeless/runaway youth in addition to the problem of being transgendered within a discriminatory and hostile society.

Loney (1998) reported that social discrimination toward transgendered individuals forces them into prostitution. Weeks et al. (1998), studying the relationship of socioeconomic status to prostitution, focused on aspects that reduce or enhance women's personal power and control that can place them at risk for HIV infection. Generally, social norms, economic need, addiction, trauma, low self-esteem, and traditional gender norms all contribute to women's inability to act in ways that will reduce their risk of HIV infection. These same forces likely influence the lives of MtF transgendered individuals as well (Loney, 1998).

Furthermore, discrimination can push MtF transgendered individuals into prostitution out of economic necessity. Unlike non-transgendered women, however, transgendered women have issues related to their gender nonconformity coupled with other issues such as race and class. An investigation into the discrimination experienced by transgendered people found many to have been fired and/or harassed on the job, to have been discriminated against within social service agencies, and to have experienced violence and harassment from society with little, if any, recourse (Green & Brinkin, 1994; Lombardi et al., in press). Additionally, transgendered women may have limited job prospects and turn to prostitution and substance abuse (Reback & Lombardi, 1999). Weeks and associates (1998) discuss the need to incorporate the realities of sex workers when designing prevention interventions. For transgendered sex workers, the importance of issues unique to both transgendered women and men (e.g., violence and discrimination and safer sex strategies for transgendered men and women) must be considered in designing state-of-the-art treatment and prevention programs.

Previous research suggests that transgendered individuals are at high risk for acquiring HIV infection and that this problem is a growing concern in many urban communities in the United States. Available studies show that MtF transgendered individuals who work as prostitutes have a high HIV infection rate (Clements et al., 1998; Gras et al., 1997; Inciardi & Surratt, 1997; Varella et al., 1996). In addition, one noteworthy community-based study of transvestite and transgendered commercial sex workers in Atlanta (Boles & Elifson, 1994) reported HIV seropositive status to be as high as 68%. The prevalence of HIV infection in this community was much higher than that of nontransgendered sex workers in the same neighborhoods.

Connecting the Transgendered Population With Health Care Services

Although HIV prevention programs have the potential to significantly reduce transgendered individuals' risk of HIV infection, reaching these individuals has been reported to be problematic. Health care service providers have found that getting transgendered individuals the services they need (e.g., substance use treatment, housing, and health care) is difficult because service providers may not want to work with transgendered clients. Furthermore, lack of sensitivity on the part of health care providers who may not respect the expressed gender identity of these individuals can adversely influence whether they will access and stay in treatment (Clements et al., 1999; Moriarty, Thiagalingam, & Hill, 1998; Transgender Substance Abuse Treatment Policy Group of the San Francisco Lesbian, Gay, Bisexual, Transgender Substance Abuse Task Force, 1995). Transgendered people may be resistant to seeking help because other transgendered individuals reported past discriminatory treatment on the part of service providers. Focus groups in San Francisco and Minneapolis found evidence of discrimination against transgendered men and women within HIV/AIDS programs (Bockting et al., 1998; Clements et al., 1999). Many programs are not sensitive to the needs of transgendered individuals (Bockting et al., 1998; Clements et al., 1999).

Substance use has been found to have important implications in HIV infection. Reback and Lombardi (1999) reported that alcohol, cocaine/crack, and methamphetamines were the most common drugs used by the transgendered women in their study (no studies have examined substances used by transgendered men). Injectable hormones and silicone are not considered illegal drugs but present problems for this population. Transgendered individuals use hormones to reconfigure their appearance so that it corresponds with their identity. Individuals may have their hormones prescribed to them by a physician. However, this requires them to have access to health care and be able to afford the treatment (either paid for out of pocket or reimbursed through health insurance). The actual cost of the office visit and prescriptions are not the only costs. Physicians may require them to undergo psychotherapy for a period of time prior to prescribing hormones (Levine et al., 1998). Other issues that influence the satisfaction of transgendered persons and whether they will return for treatment include the belief that one's doctor is not prescribing a high enough dosage or that health care providers are not sensitive to their needs. Because of these factors, many transgendered individuals purchase hormones from underground sources and administer them to each other or to themselves. This may be especially true for adolescents who are beginning to change their gender and do not have ready access to hormones. These hormones are injectable and thus have the same HIV risks as do other injectable drugs, if needles are shared.

Furthermore, the networks involved with illicit hormone use may overlap with other illicit substances. This could result in further exposure to illicit drug use and its associated HIV risks. This raises the issue of whether HIV treatment and prevention strategies should also include administering hormones to transgendered individuals so that they are not exposed to contexts that may increase their chances for infection or reinfection.

Transgendered women have been reported to inject silicone or oils (mineral and vegetable) into their bodies to quickly change their appearance, thereby allowing them to achieve a feminine appearance without causing impotence. By injecting silicone or oil with used needles, they may increase their chances of HIV infection (Inciardi & Surratt, 1997). Silicone or oil injection presents other associated problems in addition to presenting another avenue for HIV transmission;

studies have reported ill health effects associated with silicone and oil injections in nontransgender populations (Chen, 1995; Rollins, Reiber, Guinee, & Lie, 1997). Silicone and oil injection is an issue that treatment programs frequently overlook.

In sum, many transgendered individuals must navigate through a health care system that is both difficult to comprehend and insensitive to their unique care needs. As such, their health care concerns may not be treated effectively.

Improving Care for Transgendered Individuals

Transgendered individuals represent a vulnerable population at extremely high risk for HIV infection. Therefore, growing attention, both domestically and internationally, has turned to ways of improving care to this population. Australia, for example, conducted a national needs assessment on transsexuals and HIV/AIDS. This study identifies the specific needs for planning and service provision, which include the recognition of abuses of civil rights experienced by transsexuals (Bockting et al., 1998; Clements et al., 1999).

Recognizing the perils that face transgendered persons in health care and behavioral health and drug abuse treatment programs in the United States, efforts have been made to devise guidelines that may facilitate the care and treatment of transgendered individuals. Green and Brinkin (1994) and the Transgender Substance Abuse Treatment Policy Group of the San Francisco Lesbian, Gay, Bisexual, Transgender Substance Abuse Task Force (1995) have presented guidelines for the treatment of transgendered individuals. These treatment guidelines are presented in Table 2. The guidelines propose a more culturally sensitive approach to transgendered individuals. These guidelines call for acknowledging individual differences, recognizing the potential for discrimination and victimization, the many self-concept and self-esteem issues underlying their expression of their uniqueness, and the many legal and institutional issues impacting their freedom to reveal their identity as transgendered persons.

An issue that transgendered individuals believe to be critical and that is a concern of health care providers is their access to hormonal therapies and the related procedures needed to transition from one gender to another. Transgendered persons wishing sex reassignment treatments are frequently assessed to have a psychiatric diagnosis termed *gender identity discordance or gender dysphoria*. Current recommendations also require transgendered individuals to undergo psychological counseling before pursuing stages of sex reassignment therapy. The current framework developed by the Harry Benjamin International Gender Dysphoria Association endorses the use of hormones only after a period of 3 months of psychotherapy (Levine et al., 1998). Although many transgendered individuals find this to be too restrictive and psychologically invasive, these guidelines are set to protect and support individuals. Primary care providers will not consider giving hormones without at least obtaining a psychological evaluation, in which case clients will be encouraged to express a wide array of thoughts and feelings about this important, serious, and potentially harmful decision to receive hormones.

However, transgendered individuals who are also HIV-positive may face additional barriers in receiving services related to their transgender status. Contrary to some providers' beliefs, HIV sero-status is not a contraindication for either hormonal treatments or surgical sex reassignment. Although sero-status is not a barrier to these procedures, other important constraints prevent transgendered persons from pursuing their desires to realign their anatomical appearance with their perceptions of their "true" gender identity. Although it may be true that transgendered individuals are likely to exhibit higher rates of depression and anxiety than among nontransgendered HIV-positive persons (Weinrich, Atkinson, McCutchan, & Grant, 1995), most are unlikely to concede that this emotional distress is due to gender dysphoria alone. Due to the tremendous amount of social stigmatization and violence toward them, much of the anxiety and depression they experience can be linked to these stressors and not to a lack of acceptance of their biologic gender.

Because transgendered individuals are likely to encounter negative health care and substance abuse treatment experiences, it is critical that programs extend a concerted effort to achieve a higher level of cultural sensitivity with respect to caring for transgendered populations. Whereas it is more likely that health care in large HIV epicenters like Los Angeles, San Francisco, and New York will be aware of and

Table 2. Guidelines for Health Care Approaches to Transgendered Populations

1. Acknowledge that transgendered individuals can vary across many different social categories including sexual orientation.
2. Allow transgendered individuals to define their own gender rather than impose an identity upon them.
3. Acknowledge that the current social climate places transgendered individuals at risk for discrimination and violence within many public and private social contexts.
4. State the need for sensitivity training for all agencies (governmental and other).
5. Add transgender/gender identity to antidiscrimination laws and policies.
6. Protect transgendered individuals by not forcing them to disclose their transgendered status.
7. Do not impose arbitrary dress codes where they are not necessary. Where there is a reasonable requirement for a dress code, then reasonable accommodations should be made so that transgendered individuals' dignity and privacy are preserved along with the concerns of others.
8. Do not restrict transgendered individuals' access to public restroom facilities that are appropriate to a person's gender identity.
9. Substance use treatment and related programs must address the following issues:
   a) Self-esteem issues related to how they look and how they feel about themselves,
   b) Dealing with one's family and one's own level of self-acceptance,
   c) Changing one's gender on the job, finding and changing jobs,
   d) Experiencing discrimination and/or violence against them,
   e) Safe and supportive medical care including safe access to hormones, and sex reassignment surgery if they so desire,
   f) That transgendered individuals be housed in a manner consistent with the guidelines of each individual program based upon their gender self-identity, or some other reasonable accommodation. They should be asked what kind of accommodations would make them feel safe
   g) That HIV/AIDS programs address the realities of transgendered bodies as well as the issues related to transgendered men and women's participation within sex work.
10. Transgendered youth programs need to be developed so that
    a) issues relating to identity and sexuality be discussed in a manner that incorporates transgender issues. Issues relating to one's body should also be included.
    b) they have help in going through the legal and medical procedures that are required in establishing one's social gender.
    c) there is educational support to prevent youth from dropping out of school. Peer groups and role models are needed to help support transgendered youth.
11. Furthermore, it is important for researchers to categorize male-to-female and female-to-male transgendered individuals as such and not conflate them with gay men or lesbians (unless as appropriate to an individual's sexual orientation in his or her preferred gender) as well as to acknowledge the variation that exists between transgendered individuals, to be sensitive to the lives of transgendered individuals, and treat them with dignity and respect. This includes referring to them as the gender with which they identify.

Adapted from Green and Brinkin (1994) and the Transgender Substance Abuse Treatment Policy Group (1995).

follow proposed guidelines for treatment and prevention programs (Table 2), providers in other large cities and even smaller rural communities need to be alerted to the deficiencies in care to transgendered populations. Transgendered individuals reside in all regions and in rural, suburban, and urban locales. It is likely that transgendered individuals will need to seek health services within small towns and rural areas and, thus, require the same sensitivity.

Programs that provide transgendered individuals with access to culturally sensitive prevention and treatment services are imperative. Model programs exist in San Francisco and in New York (Warren, Capozuca, Pols, & Otto, 1996) and attempt to blend the perspectives of health care and service providers and transgendered clients. Specific educational materials and outreach programs for sex workers, particularly using peer educators, are extremely useful. The successes of these model programs suggest that such strategies should extend beyond the prevention and early intervention level to treatment and tertiary care programs. For example, Grimaldi and Jacobs (1998) reported that by making hormones easily available for transgendered women, they were able to increase the participation and engagement of these women within their HIV program.

In summary, there is an urgent need for changes in HIV prevention strategies and in the provision of culturally sensitive health care for transgendered individuals, not just at the level of prevention but also at the

level of treatment. Beginning efforts to establish individualized special care clinics for the treatment of transgendered individuals who are HIV infected are evidenced in some large cities such as Los Angeles and San Francisco. Just as special care units and clinics for HIV-infected gay and bisexual male clients have been successful in presenting models for practice, these programs should provide guidance to others in constructing effective and culturally sensitive services. Training of health care professionals in the unique needs and concerns of this population is warranted. Additionally, because other types of social discrimination, related to race, ethnicity, and social status, also affect many transgendered men and women, specific attention should be given to communities of color where risk may be even higher. It is clear that HIV risk behaviors are common among transgendered populations, and to some extent both transgendered women as well as transgendered men may be at higher risk than gay and bisexual and intravenous drug user populations. Because of poverty and survival sex, MtF and to a lesser extent FtM individuals may continue to engage in high-risk sexual and injection drug use behaviors. Awareness of and attention to the unique concerns of these groups may result in significant improvements in providers' ability to recruit and successfully treat these individuals.

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